IOK/60/2022

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## Call for Inputs: Human Rights Council resolution 49/12 on the rights of persons with disabilities

**1(a). Does your country have laws, policies, plans, strategies or programmes at any level of government relating to individualized support for persons with disabilities? In particular initiatives related to:**

1. **Communication: Support to overcome barriers that limit the ability to communicate and be understood (e.g., sign language interpretation, tactile interpretation, assistive technology and software, easy-to-read and plain language, captioning, augmentative and alternative communication, among others);**

Deaf, deaf-blind, and persons with hearing disabilities or speaking disabilities are entitled to interpretation under many different acts. For example, under the Basic Education Act[[1]](#footnote-1), students are entitled to interpretation based on need. (However, this might leave the hearing children of deaf parents, whose first language is sign language, in a precarious situation as they are not entitled to education in their mother tongue. Hence, their studying results are not necessarily as good as their peers' as they have to study in their other language, Finnish or Swedish.)

Under the Disability Interpretation Act[[2]](#footnote-2), the deaf, deaf-blind, and persons with hearing disabilities or speaking disabilities are entitled to interpretation if they can not get it under any other law. Under the Act, deaf-blind are entitled to a minimum of 360 hours of interpretation during a calendar year, and other groups are entitled to a minimum of 180 hours of interpretation during a calendar year. During the last years, the amount of persons with disabilities entitled to interpretation services has stayed approximately the same. In 2021, 107,3 people per 100 000 inhabitants were entitled to interpretation services for persons with disabilities[[3]](#footnote-3).

Finnish Centre for Easy Language produces training and materials in easy language (such as novels). However, the funding of the Centre comes from Funding Centre for Social Welfare and Health Organisations (STEA), which means that it is project-based and not per se public funding or regulated by law. This leaves the Centre in a financially precarious position. Textphone service faces the same challenges. Textphone is meant for people who are deaf, hard of hearing or have a speaking disability. Via the textphone service, they can call the person or service they wish via call center. Textphone is also a way for an able-bodied person to contact someone who cannot answer phone calls otherwise. The STEA also funds the textphone service, and as the number of calls is getting lower, the funding is about to stop at the end of the year. However, there's no other service that would be completely corresponding. Either the other services have more limited opening hours, or they can not be used for spontaneous phone calls. Other services are only meant for persons with disabilities, meaning that able-bodied can not use the service to contact persons who are not otherwise able to answer phone calls.

1. **Decision-making: Support to make decisions and exercise legal capacity. This includes assistance to: (a) obtain and understand information, (b) evaluate the possible alternatives and consequences of a decision, (c) express and communicate a decision, and/or (d) implement a decision (e.g., support agreements, peer support, self-advocacy support, advance directives, crisis support, financial management assistance, among others);**

There's no specific mention of decision-making support in the Disability Services Act[[4]](#footnote-4). However, officials can grant it under "other services" mentioned in the Act. As there's no specific regulation, it is difficult to find information on how much the service is granted. Probably many relatives and trustees offer decision-making support unofficially. In general, this is not an issue except if there's a risk of conflict of interest.

To be eligible for personal assistance in Finland, the person has to have the resources to define the contents and modalities of implementing personal assistance (the so-called "resource criteria"). The resource criteria means that many persons with disabilities who need decision-making support are not eligible for personal assistance. In the government draft proposal for the new Disability Services Act, decision-making support is included as a service. However, according to the draft proposal, the decision-making support would be offered very scarcely. It is unclear if the amount offered would be enough to fill the resource criteria for personal assistance.

1. **Mobility: Support for personal mobility and access to affordable and available quality mobility assistance (e.g., mobility aids, assistive technologies and products (prostheses, orthotics, wheelchairs), animal assistance, point-to-point and paratransit transport, among others);**

Many laws and statutes regulate that persons with disabilities and temporary mobility support needs (for example, due to bone fractures) have the right to use mobility aids for free. Persons with disabilities can also get personalized mobility aids based on their needs. According to the Disability Services Act, counties must grant persons with disabilities reasonable transport services. According to the Disability Services Statute[[5]](#footnote-5), all persons who have significant difficulties using public transport are entitled to 18 one-way free time journeys per month and all necessary work and studying journeys. In 2021 there was a slight drop in people receiving transportation services for persons with disabilities. The drop is probably due to the pandemic, and many persons with disabilities were self-isolated for fear of infection. In 2020, 1625,3 people per 100 000 inhabitants received transportation services, but in 2021 the number was 1558,1 people per 100 000 inhabitants[[6]](#footnote-6).

However, some mobility aids are difficult to get. There are only around 60 assistance dogs in Finland, whereas the biggest NGO in Finland for persons with mobility disabilities has stated that the need would be for around 150 to 200 assistance dogs[[7]](#footnote-7). According to previous national guidance by the ministry of social affairs and health, assistance dogs are not granted as medical rehabilitation which probably affects the low number of assistance dogs currently in use. However, the deputy parliamentary ombudsman stated in 2018 that this guidance is against the law and puts persons needing a guide dog or an assistance dog in different positions[[8]](#footnote-8). The ministry of social affairs and health is supposed to give new national guidance on by what criteria assistance dogs can be granted to a person with disability by the end of 2022.

1. **Assistance with daily living activities: Support to assist persons with disabilities in a one-to-one human relationship to perform daily life activities like getting up, bathing, dressing, grooming, going out, cooking, cleaning, guiding, shopping, or doing laundry (e.g., full or part time professional personal assistance, third person support allowance, informal personal assistance, household cleaner, among others);**

Under the Disability Services Act, personal assistance is available for those individuals who need the help of another person in daily activities. People who need assistance mainly due to their age are not included in the act. As mentioned above, in order to be eligible for personal assistance, the individual must have the resources to define the contents and modalities of implementing personal assistance. Many persons with intellectual disabilities are therefore excluded from the implementation of this service. In April 2022, the CRPD committee ruled that Finland had discriminated against a person with physical and intellectual disabilities when they hadn't granted them personal assistance for activities inside the home due to not filling the so-called resource criteria.[[9]](#footnote-9) It was ruled as discrimination as no other service was offered to him that would've made it possible for them to live independently in their own home.

There has been quite sharp rise in the amount persons receiving personal assistance services. In 2019, the amount was 491,5 people per 100 000 inhabitants, and in 2021 the amount was 521,2 people per 100 000 inhabitants[[10]](#footnote-10).

1. **Housing and accommodation: Support in relation to housing and living arrangements in the community, including home modifications (e.g., housing information and assistance, home support, supported living services, financial support for housing, among others);**

According to the Disability Services Act, counties must pay for reasonable home modification expenses if a person with a disability needs them to survive in their daily lives. Counties can grant a person with a disability supported living, sheltered accommodation, or intensive sheltered accommodation under Social Welfare Act[[11]](#footnote-11), Disability Services Act, or Intellectual Disability Services Act[[12]](#footnote-12).

There's been a quite significant drop in home modifications in all age categories in 2021 compared to two previous years. In 2020 202,4 persons got home modification per 100 000 inhabitants. In 2021, it was 187,4 per 100 000 inhabitants[[13]](#footnote-13). The pandemic might have affected this.

1. **Family and household support: Support to families and households with members with disabilities (e.g., informal support for persons with disabilities, including care-related work leave and capacity building for informal care and support, community-based network and community mobilization programmes, peer-support groups, localized intervention programmes, circle of support, early childhood support, respite care, among others); and**

In Finland, there are approximately 50 000 official caregivers[[14]](#footnote-14). The estimated amount of informal care far exceeds these numbers. According to the Caregiver Support Act[[15]](#footnote-15), counties must give caregivers appropriate training, days-off, monetary compensation based on the hours, and substitute carers when caregivers have their days off. During pandemic there has been disruptions in these services (please see answer to the question 5).

Many NGOs offer different kind of peer support groups and other courses. Sometimes adaptation training can be granted under Disability Services Act. Sometimes National Social Security Institution Kela funds adaptation training participation.

1. **Disability-related extra costs: Financial support to pay services and goods, including personalized budgets and direct payments (e.g., cash transfers beyond income replacement, additional funds to cover support services, among others).**

Under the Disability Services Act, persons with disabilities are entitled to compensation for the extra costs that may come from special clothes or a specific diet. Counties also need to compensate half of the price of the equipment that people with disability need in their daily life. However, necessary modifications to everyday objects are to be compensated completely.

National Social Security Institution Kela pays disability support. Under the Disability Support Act[[16]](#footnote-16), there's different support for persons with disabilities under 16 years old and those over 16 years old. Both disability benefits are divided into three levels based on the degree of disability, from 74,19 euros per month to 335,69 euros per month. There has been some rise in the number of people 16 years or older receiving disability allowance per 1000 inhabitants in the same age category. In 2019, 2,5 people per 1000 inhabitants received an allowance. In 2021, 2,7 people per 1000 inhabitants received disability allowance[[17]](#footnote-17).

1(b). **What are the government institutions, departments and ministries in charge of budgeting, financing and implementing the above?**

Municipalities, in the future counties, and National Social Security Institution Kela (a separate state institution) are responsible for producing and implementing disability services and benefits. In part, municipalities and counties decide independently on the funding of these services, and in part, the state decide on the funding. In most of the cases, the ministry in charge of the legislation is the ministry of social affairs and health. In some cases, it can be the ministry of education and culture.

1(c). **How is the social and solidarity economy (third sector, non-profit sector), particularly the disability sector, involved in budgeting, financing and implementing the above (1(a))?**

Even though NGOs produce some disability services in Finland, the responsibility for securing these services lies within municipalities, counties, and state. In essence, almost all services are funded publicly.

1(d). **How are persons with disabilities and their representative organizations involved in the design and monitoring of the above (1(a))?**

Under Municipality[[18]](#footnote-18) and County Acts[[19]](#footnote-19), all municipalities and counties must set up a disability committee so that persons with disabilities and their relatives are engaged and involved in the planning, influencing and monitoring disability services.

Under the Ministry of Social Affairs and Health there is an Advisory Board for the Rights of Persons with Disabilities, VANE. The Advisory Board for the Rights of Persons with Disabilities is the national coordinating mechanism for the UN Convention on the Rights of Persons with Disabilities. Its function is to promote national implementation of the Convention and to take into account the rights of persons with disabilities in all aspects of government. The board comprises representatives of ministries, persons with disabilities and their families, labour market organizations, and representatives from regional and local government.

The Human Rights Centre (HRC) has, together with the Human Rights Delegation and the Parliamentary Ombudsman, a statutory special task to promote, protect and monitor the implementation of the United Nations Convention on the Rights of Persons with Disabilities.

After Finland ratified CRPD, DPOs have been consulted more systematically in legislative drafting.

2(a). **Does your country have legislation or policies, at any level of government, regulating and coordinating a care and support system that considers the areas mentioned in 1(a) above? Please provide references to the documentation.**

Many different laws and statutes regulate disability benefits, support, and services. In each answer, the main acts and statutes regarding each question are supplied.

2(b). **If yes, please describe how the care and support system is financed and what is the percentage of the eligible population covered.**

Most of the welfare services in Finland, disability services and benefits included, are funded by taxes. Some isolated services and support are funded by Funding Centre for Social Welfare and Health Organisations (STEA). STEA's money comes from national gamble monopoly Veikkaus Oy.

3. **Does your country have a strategy to develop legislation, policies and programmes to enable the development of support systems as described in 1(a) above which includes targets, indicators and an accountability mechanism? Please provide references to the documentation.**

Currently, there’s the National Action Plan on the UN Convention on the Rights of Persons with Disabilities[[20]](#footnote-20). The action plan determines the measures that will be taken to promote the implementation of the Convention in different administrative branches during the second action plan period 2020–2023.

The Advisory Board for the Rights of Persons with Disabilities, VANE, was responsible for drawing up the Action Plan. The Advisory Board includes representatives of disability organisations, labour market organisations and the ministries with key significance to the rights of persons with disabilities. Disability organisations and other stakeholders have been consulted during the process of drawing up the Action Plan to obtain information about the matters that according to the Convention should primarily be promoted in the Action Plan.

The Action Plan comprises 110 measures, and the ministries have committed themselves to their implementation. A responsible party or parties have been indicated for each measure. The implementation of the measures will be monitored during the action plan period and assessed at

the end of the period.

The Action Plan emphasises the importance of social inclusion of persons with disabilities in the changing operating environment and the importance of accessibility as a precondition for implementing the other rights. One of the main objectives of the Action Plan is to increase awareness of the rights of persons with disabilities and to mainstream these rights in different

administrative branches and more widely in society.

4. **Please provide data on persons with disabilities and families and households accessing care and support systems as described above in 1(a) and 2(a).**

Please see each answer for the statistics regarding each service.

5. **Please provide data on the impact of the COVID19 pandemic on persons with disabilities and families and households with members with disabilities (death rates disaggregated by disability status, death rates in institutions compared to those living in the community, impact on income as a consequence of disruption in support or increased support and care demands, disruption in support services, among other).**

According to a study by the Finnish institute for health and welfare[[21]](#footnote-21), people using personal assistants had difficulties during the pandemic getting enough assistance. 70 % of the respondents mentioned that they had more problems receiving the personal assistance they needed than before the pandemic. Some of the respondents had difficulties using personal assistance as, at the beginning of the pandemic, some housing services for persons with disabilities limited the possibility of receiving guests from outside. Compared to persons without disabilities, people using personal assistance felt more lonely and worried about potential infection and infecting their close contacts. Their time with their family members had also decreased more than that of the rest of the population. Especially at the beginning of the pandemic, the respondents also reported difficulties in gaining medical protective equipment. Many also reported difficulties getting physiotherapy. In the open answers, respondents mentioned that the lack of physiotherapy had affected their overall condition. Over 60 % of the respondents felt that the restrictive measures to stop the spread of the disease were understandable under the circumstances, and only 17 % felt that there were too many restrictions. However, most of the respondents were not living in the housing services, where restrictions were heavier. 61 % of the respondents were a lot or a little worried that they would be discriminated against in health care and that they would be denied intensive care based on their disability. The fear of being discriminated against in health care has probably affected the acceptance rate of restrictions to stop infections among the respondents.

Persons with disabilities reported more often that their financial situation had worsened during the pandemic than the rest of the population. Experience of the worsened financial situation was especially evident among the persons with disabilities born outside of Finland. Persons with disabilities born outside of Finland also reported more conflicts with family members and more trouble sleeping compared to other persons born outside of Finland and persons with disabilities born in Finland.[[22]](#footnote-22)

During the pandemic, the Parliamentary Ombudsman investigated several complaints regarding restrictive measures in housing services for persons with disabilities and older people. In several instances, the Parliamentary Ombudsman found that some restrictions were against the law or objectionable in other ways. For example, the ombudsman stated that it was illegal when a resident had been quarantined only due to meeting other people outside the housing services[[23]](#footnote-23). Only infectious diseases specialists can order a person to quarantine. In another case, the ombudsman stated that the housing services had acted in a reprehensible manner when restricting the resident's use of personal assistance[[24]](#footnote-24). Even though the restrictive measures are meant to protect the right to health and life, the housing services are still obligated to ensure that persons with disabilities can use the services they're entitled to.

Especially at the beginning of the pandemic, many services used by caregivers were temporarily halted. Many caregivers couldn't have their legal days off when housing services couldn't receive short-term residents. 35 % of municipalities reported trouble organizing the days off for caregivers. 53 % of municipalities reported trouble organizing other legal services that would allow caregivers to have some time off (for example, peer support).[[25]](#footnote-25) In a query that targeted caregivers, 84 of the respondents in Finland reported that the pandemic harmed how much they could be in contact with their friends and family. 79 % of respondents reported feeling less free and more housebound. 56 % of female respondents mentioned that the temporarily halted health and social services for the person they're the caregiver for has had a negative impact on their life. 74 % were worried about what would happen to the people they are the caregiver for in case they would get the covid-19 infection. According to the query, the youngest caregivers who often cared for their children bore the brunt of the negative impacts on caregivers.[[26]](#footnote-26)

Currently, there are no covid-19 restrictions in force in Finland. The service level seems to have recuperated well from the pandemic and restrictions, though it takes time before the care debt is paid off, especially in dental care. However, there has been news that in some housing services, quite strict restrictions are still in use which raises a question on how well the residents' right to self-determination is realized. The pandemic has shown that special attention needs to be paid to the rights of disabilities and other marginalized groups in the public contingency plans so that persons with disabilities are protected during a crisis, per article 11 in CRPD.

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1. Basic Education Act, section 10 (in Finnish): <https://www.finlex.fi/fi/laki/ajantasa/1998/19980628#L4P10> [↑](#footnote-ref-1)
2. Disability Interpretation Act (in Finnish): <https://www.finlex.fi/fi/laki/alkup/2010/20100133> [↑](#footnote-ref-2)
3. Sotkanet.fi, Statistical information on welfare and health in Finland, number of people entitled to interpretation services under Disability Interpretation Act <https://sotkanet.fi/sotkanet/en/taulukko/?indicator=sw7xBQA=&region=s07MBAA=&year=sy5zsjbS0zUEAA==&gender=t&abs=f&color=f&buildVersion=3.0-SNAPSHOT&buildTimestamp=202109301228> [↑](#footnote-ref-3)
4. Disability Services Act (in Finnish): <https://www.finlex.fi/fi/laki/ajantasa/1987/19870380> [↑](#footnote-ref-4)
5. Disability Services Statute (in Finnish): <https://www.finlex.fi/fi/laki/ajantasa/1987/19870759> [↑](#footnote-ref-5)
6. Sotkanet.fi, Statistical information on welfare and health in Finland, the amount of persons receiving transport services under Disability Services Act <https://sotkanet.fi/sotkanet/en/taulukko/?indicator=szaNAgA=&region=s07MBAA=&year=sy5zsjbS0zUEAA==&gender=t&abs=f&color=f&buildVersion=3.0-SNAPSHOT&buildTimestamp=202109301228> [↑](#footnote-ref-6)
7. Finnish institute for welfare and health: report on assistance dogs (in Finnish): <https://www.julkari.fi/handle/10024/143948> [↑](#footnote-ref-7)
8. Deputy Parliamentary Ombudsman’s statement regarding assistive technology that is granted as medical rehabilitation (in Finnish): <https://www.oikeusasiamies.fi/r/fi/ratkaisut/-/eoar/1067/2019> [↑](#footnote-ref-8)
9. The ruling by the CRPD committee: <https://um.fi/documents/35732/0/YKn+vammaisten+henkil%C3%B6iden+oikeuksien+komitean+ratkaisu.pdf/54c2bf15-5366-60b0-eb3a-daf1dcf0f572?t=1649416758767> [↑](#footnote-ref-9)
10. Sotkanet.fi, Statistical information on welfare and health in Finland, the amount of persons receiving personal assistance services under Disability Services Act <https://sotkanet.fi/sotkanet/en/taulukko/?indicator=szYzBAA=&region=s07MBAA=&year=sy5zsjbS0zUEAA==&gender=t&abs=f&color=f&buildVersion=3.0-SNAPSHOT&buildTimestamp=202109301228> [↑](#footnote-ref-10)
11. Social Welfare Act (in Finnish): <https://finlex.fi/fi/laki/ajantasa/2014/20141301> [↑](#footnote-ref-11)
12. Intellectual Disability Services Act (in Finnish): <https://www.finlex.fi/fi/laki/ajantasa/1977/19770519> [↑](#footnote-ref-12)
13. Sotkanet.fi, Statistical information on welfare and health in Finland, the amount of persons receiving home modifications under Disability Services Act <https://sotkanet.fi/sotkanet/en/taulukko/?indicator=sw7NBgA=&region=s07MBAA=&year=sy5zsjbS0zUEAA==&gender=t&abs=f&color=f&buildVersion=3.0-SNAPSHOT&buildTimestamp=202109301228> [↑](#footnote-ref-13)
14. Sotkanet.fi, Statistical information on welfare and health in Finland, the amount of persons receiving caregiver support: <https://sotkanet.fi/sotkanet/en/taulukko/?indicator=sy4PAwA=&region=s07MBAA=&year=sy5zsjbS0zUEAA==&gender=t&abs=f&color=f&buildVersion=3.0-SNAPSHOT&buildTimestamp=202109301228> [↑](#footnote-ref-14)
15. Caregiver Support Act (in Finnish): <https://www.finlex.fi/fi/laki/ajantasa/2005/20050937> [↑](#footnote-ref-15)
16. Disability Support Act (in Finnish): <https://www.finlex.fi/fi/laki/ajantasa/2007/20070570> [↑](#footnote-ref-16)
17. Sotkanet.fi, Statistical information on welfare and health in Finland, number of persons receiving disability allowance per 1000 inhabitants <https://sotkanet.fi/sotkanet/en/taulukko/?indicator=s3YKAgA=&region=s07MBAA=&year=sy5zsjbS0zUEAA==&gender=t&abs=f&color=f&buildVersion=3.0-SNAPSHOT&buildTimestamp=202109301228> [↑](#footnote-ref-17)
18. Municipality Act, Section 28 (in Finnish): <https://www.finlex.fi/fi/laki/ajantasa/2015/20150410#O2L5P28> [↑](#footnote-ref-18)
19. County Act, Section 32 (in Finnish): <https://www.finlex.fi/fi/laki/alkup/2021/20210611#Pidm45949345536976> [↑](#footnote-ref-19)
20. National Action Plan on the UN Convention on the Rights of Persons with Disabilities (in Finnish): <https://julkaisut.valtioneuvosto.fi/handle/10024/162687> [↑](#footnote-ref-20)
21. Finnish institute for health and welfare (2021): Experiences from people using personal assistance during corona epidemic (in Finnish): <https://www.julkari.fi/handle/10024/142612> [↑](#footnote-ref-21)
22. Päivi Sainio, Marja Holm, Jonna Ikonen, Marika Korhonen, Päivi Nurmi-Koikkalainen, Suvi Parikka, Natalia Skogberg, Anna Väre, Päivikki Koponen, Seppo Koskinen (2021): The effects of covid pandemic to the lives of persons with disabilities (in Finnish): <https://journal.fi/sla/article/view/103240> [↑](#footnote-ref-22)
23. Statement by Parliamentary Ombudsman regarding illegal quarantine in housing service (in Finnish): <https://www.oikeusasiamies.fi/r/fi/ratkaisut/-/eoar/6353/2020> [↑](#footnote-ref-23)
24. Statement by Parliamentary Ombudsman regarding the restrictions to the use of personal assistant in housing services (in Finnish): <https://www.oikeusasiamies.fi/r/fi/ratkaisut/-/eoar/4247/2020> [↑](#footnote-ref-24)
25. Finnish Institute for health and welfare (2021): Covid-19 restrictions harmed support for caregivers (in Finnish): <https://www.julkari.fi/handle/10024/142757> [↑](#footnote-ref-25)
26. Sihto, T., Leinonen, E., Kröger, T. (2022): Caregiving and the COVID-19 pandemic: everyday life, quality of life and availability of services for caregivers during the corona pandemic (in Finnish): <https://jyx.jyu.fi/handle/123456789/80448> [↑](#footnote-ref-26)